HEREDITARY BLINDNESS

The Report of the Prevention of Blindness Committee

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EUGENISTS will be very gratified by the findings of the Prevention of Blindness Committee of the Union of Counties Associations for the Blind dated April 1933. The recommendations of this Committee often lead to immediate action, and they are read widely in the right quarters. The members of this Committee consist of persons who have to do with the care, cure, or education of the blind, and who have only the interests of the blind at heart. Its funds are charitable.

The material about to follow consists of extracts that I have selected.

The Report opens with some "General Observations." It says: "A mass of data has been collected by individual ophthalmologists, but the correlation of the data is a matter for the genetic expert who has already done a good deal of work on it." . . . "It is hoped that in the future Public Health Departments may be willing to undertake a certain amount of investigation of cases which come before them in the course of their work, with a view to submitting them to scientific analysis by a genetic expert." . . . "We can point to cases in which the marriage of one man or woman suffering from, say, retinitis pigmentosa, has resulted in some forty cases of blindness in subsequent generations. All will agree that such a possibility is intolerable, but we have no idea what proportion of the total number of persons suffering from some such disease has married with no ill result to their descendants."

Proceeding then to discuss its new form for the certification of blindness (Appendix II) the Committee writes as follows: "This form of report will in certain cases indicate the possibility of hereditary disease which requires further investigation, but neither the ophthalmologist nor the specialist in heredity would be able to form an opinion as to the hereditary nature of the disease *without a pedigree*" (my italics). The consultant, it goes on to say, would not be justified in giving advice against parenthood "unless his opinion on the disease *qua* disease is reinforced by the evidence of a pedigree"—which should contain all the relevant information and apply, as strictly as possible, the principles set out in Appendix I to the Report. "It is, however, possible for an ophthalmologist, in consultation with a genetic expert, to state for any individual whose family history has been carefully investigated, the degree of risk of blindness in succeeding generations which parenthood would involve." Further: "Hereditary blindness, in common with other inherited tendencies, is inherited not only through persons actually suffering from it, but also (and in some diseases predominantly) through persons who, though not themselves affected, are nevertheless carriers of the taint. Abstention from parenthood by blind persons who are the subject of hereditary eye disease is not therefore of itself sufficient. An intermarriage of blind persons should always be approached with caution, and it may be said that parenthood of persons suffering from inheritable blindness is inadvisable unless the ophthalmologist is prepared to say that the risk is so slight as to be negligible."

Here follows a "Classification of the main hereditary eye diseases," some causing blindness (*a*), and less serious ones causing grave visual defects (*b*).

(*a*) Retinitis pigmentosa.
Hereditary optic atrophy (Leber).
Anophthalmos.
Familial macular degeneration.
Microphthalmos.
Oxycephaly.

(*b*) Albinism.
Aniridia.
Cataract (congenital and lamellar).
Coloboma of the iris.
Congenital night-blindness.
Ectopia lentis.
Familial degeneration of the cornea.
Glioma of the retina.
Buphthalmos (slight hereditary tendency).

Myopia is mentioned in a special paragraph. "The fact that the liability to myopia may be accentuated in the children of myopic parents is admitted."

Under the heading "Transmission of Disease: The View of the Eugenist" appears the following interesting statement:

"The transmission of disease may be considered purely from a eugenic point of view, regardless of all other considerations whatsoever. From this point of view, a eugenist would probably urge that ascertained facts would justify the following conclusions:

(*a*) Any man or woman who has had aniridia, congenital cataract, glioma of the retina, hereditary opacity of the cornea or ectopia lentis, microphthalmos, retinitis pigmentosa, and of whom either parent has been similarly affected, is likely to transmit the defect and should abstain from parenthood.

(*b*) Any normal parents who have more than one child affected with any one of the above-mentioned diseases, or with buphthalmos or total colour blindness, should have no more children, and such children as they have should abstain from parenthood—whether they themselves be affected or not. Even if the parenthood of such children does not lead at once to the manifest reproduction of the disease, it inevitably adds to the latent defect in the population, which becomes manifest when two people carrying such latent defect marry and have children.

(*c*) If in all stocks in which Leber's Disease (hereditary optic atrophy) has occurred more than once, the sisters of affected males were to abstain from parenthood, the disease would be almost exterminated, except for sporadic cases of no genetic significance. In general, there is no risk to the descendants of men who are suffering from Leber's Disease; the cases in which they transmit the disease are very rare, but should be borne in mind, and if one such case in a family has occurred, all other affected members of *that* stock should be regarded as liable to transmit."

The Committee sums up the present position with five recommendations under the heading "General Conclusions." Here it points out that as a Committee it cannot subscribe to all the limitations on parenthood proposed by eugenists, if only for the reason that some of the diseases do not cause certifiable blindness.

However, they would like to see (1) more complete statistics, and (2) better certification of the blind. (Both of these steps were urged by me in letters to the Joint Committee of London Ophthalmological Hospitals, the Ministry of Health, and the Council of British Ophthalmologists in 1930 and 1931, and in an article sent to the *British Medical Journal* in 1931, printed in 1932.) And they state their conclusions as follows:

From the point of view of the causation of blindness, the most important inheritable diseases which have to be considered are retinitis pigmentosa and Leber's Disease.

If a member of a stock in which there is definitely inheritable disease causing blindness, even if the disease is not manifest in his or her case, marries, he or she should be strongly urged to consult an ophthalmologist, who, with the assistance of a pedigree, would advise as to abstention from parenthood. This statement need not apply to males in a stock carrying Leber's Disease, except in the very exceptional families in which males have been known to transmit.

Unless there is medical evidence to show that the case does not fall within the hereditary class, a blind person contemplating marriage should seek the advice of a competent ophthalmologist before marriage, in view of the complex nature of the problem and the serious handicap imposed upon the children of persons suffering from inheritable eye disease. The ophthalmologist will no doubt obtain a pedigree and, if necessary, consult a genetic expert.

The Report is excellent and is a real justification for eugenics; it is a very fair résumé of the facts and the members of the Committee are to be congratulated on

making such a difficult subject clear and understandable. It is quite possible that the work of the *Eugenics Society* has hastened and assisted the findings of this Committee. It will be at once apparent that the work of the *Eugenics Society* must continue; this Report shows that only the most serious and obvious dysgenic factors have been dealt with.

The Committee points out that it is presenting the report of a Prevention of Blindness Committee and not the report of a Committee for the Prevention of Eye Disease, and that it has considered the question from the medical and not the social aspect. It states that albinism, aniridia, congenital cataracts, ectopia lentis, congenital degeneration of the cornea, glioma of the retina, and buphthalmos, " would not, in all probability, cause certifiable blindness."

I should have preferred the statement, " might not, possibly, cause certifiable blindness." I have seen many persons certifiably blind with these diseases. They are terrible afflictions and always cause some degree of blindness. I can imagine the acute anxiety of any of the members of the Committee viewing their offspring for the first time, if any of these diseases were " in the family." In my opinion death is preferable to most of them and their victims are terribly handicapped in the struggle of life, and find themselves shut off from hosts of occupations and recreations. Employers employ them with diffidence. The treatment of glioma of the retina is mutilating, and the death of a child with this disease is sometimes frightful. In 25 per cent. of cases the disease is bilateral, and excision of both eyes to save the life of the child may be necessary.

The remarks with regard to myopia are so short that perhaps the seriousness of this disease might not be appreciated. About 20 per cent. of our registered blind are blind through myopia, which is a hereditary condition not yet fully understood. In addition to the blind, immense numbers of persons have very defective vision due to the higher degrees of myopia. Many people suffering therefrom do wish to avoid inflicting a similar handicap on their children when the risk is explained to them. The man in the street is eugenically minded and needs no compulsion; only the mentally deficient require this.

Under the heading " General Conclusions," the Committee, as I have pointed out, stresses the importance of securing more complete statistics and better Certification of the Blind. There are important genetical reasons for these measures. For instance, it is possible there are one million persons in Great Britain who are blind in one eye. Now a person who is blind in one eye from an inherited defect might have, say, four children each blind in one eye, or possibly four children two of whom are blind in both eyes. We eugenists stress the fact that every child has the right to be born fit in fit surroundings: we respect the rights of the unborn child.

From my work at four large hospitals in the poorest parts of London I have been led to the conclusion that only about one in five of the blind are registered. The certification of a blind person is nobody's business. The blind person cannot be responsible, for obvious reasons, and he often objects to certification; the surgeons at the clinics are often loath to mention the subject, in the rare event of their thinking about it or knowing the necessary standards and procedure. The Public Authorities in London and many other places do not pay an adequate fee for the examination, and often no fee at all, as the work is not considered important, apparently. The British Medical Association has said it is not part of the duty of the surgeons of voluntary hospitals to undertake this work. Hence the Committee's recommendations on this matter.

It is to be hoped that, as funds permit, the excellent work of the Prevention of Blindness Committee will be extended. Indeed, the Committee is working on parallel lines with the *Eugenics Society*, and I consider that the data which will be assembled when its recommendations are adopted will have considerable value. There is more public sympathy for the blind than for the mentally deficient. The Report, which deserves to be widely read and studied, may be obtained from The Secretary, Prevention of Blindness Committee, 66 Victoria Street, London, S.W.1.